

# Recommendations for the Critical Care Management of Devastating Brain Injury: Prognostication, Psychosocial, and Ethical Management

## A Position Statement for Healthcare Professionals from the Neurocritical Care Society

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**Abstract** Devastating brain injuries (DBIs) profoundly damage cerebral function and frequently cause death. DBI survivors admitted to critical care will suffer both intracranial and extracranial effects from their brain injury. The indicators of quality care in DBI are not completely defined, and despite best efforts many patients will not survive, although others may have better outcomes than originally anticipated. Inaccuracies in prognostication can result in premature termination of life support, thereby biasing outcomes research and creating a self-fulfilling cycle where the predicted course is almost invariably dismal. Because of the potential complexities and controversies involved in the management of devastating brain injury, the Neurocritical Care Society organized a panel of expert clinicians from neurocritical care,

neuroanesthesia, neurology, neurosurgery, emergency medicine, nursing, and pharmacy to develop an evidence-based guideline with practice recommendations. The panel intends for this guideline to be used by critical care physicians, neurologists, emergency physicians, and other health professionals, with specific emphasis on management during the first 72-h post-injury. Following an extensive literature review, the panel used the GRADE methodology to evaluate the robustness of the data. They made actionable recommendations based on the quality of evidence, as well as on considerations of risk: benefit ratios, cost, and user preference. The panel generated recommendations regarding prognostication, psychosocial issues, and ethical considerations.

**Keywords** Devastating brain injury · Critical care management · Neurocritical care · Evidence · Guidelines · Recommendations · GRADE

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## Introduction

Clinicians use various labels to describe patients who have suffered severe neurological insults. The term “catastrophic brain injury” has been used as a legal definition, and the equally emphatic “devastating brain injury” (DBI) is preferred.

The implicit goal of such labels is to identify a population experiencing imminent threat to life as a consequence of brain injury. Such early identification allows the delivery of “...sound neurologic critical care that will improve perfusion to the brain and (that) has the potential to turn a devastating brain injury into a salvageable one” [1]. Improved perfusion also confers secondary benefit by improving the viability of other organ systems and preserving the opportunity to consider organ donation if the situation progresses to either brain death or a decision to withdraw therapy.

The application of appropriate critical care in these circumstances avoids self-fulfilling nihilism, while simultaneously increasing confidence in the accuracy of clinical assessment by virtue of increased observation. There are no established guidelines for the immediate assessment and management of such injury. Our principal aim was to address this deficit by reviewing the available evidence and to guide clinical decision making in DBI.

## Methods

A multidisciplinary group of clinicians was recruited from the membership of the Neurocritical Care Society. Consensus on topics of inquiry was derived predominantly via telephone conferences held once or bimonthly, as well as during several in-person meetings. The panel formulated clinical questions of interest. Panelists performed literature searches in Medline, Embase, CINAHL, and Cochrane databases for each topic area using MeSH keywords (see Electronic Supplementary Material). The search scope excluded animal and pediatric studies and was limited to English language journals. There were no date restrictions. The initial search retrieved 9,826 publications, of which 5,219 were excluded based on the specified criteria. Panelists reviewed 4,907 studies in total, and the details of 1,266 studies were abstracted. Additional references were identified based on hand searches of the bibliographies of these publications. A subset of these references was used to form the basis for the guidelines in *Part 1: Ethical and Psychosocial Considerations in DBI*, while the rest were used to develop recommendations for *Part 2: Medical Management*.

Quality of evidence was assessed as very low, low, moderate, or high using GRADE principles [2]. In

generating recommendations, panelists considered the strength of evidence behind the outcomes of interest, as well as any relevant issues pertaining to risk:benefit ratio, cost, and patient/clinician values and preferences [3]. Final recommendations were designated as strong or weak. In the significant absence of published research, the panel issued recommendations that were primarily based on expert opinion.

Strong recommendations are those where the tradeoff of risk and benefit is clear enough and precision evident enough that most clinicians, despite differences in the patient’s values, age, and health would make the *same* choice. Weak recommendations are those where the tradeoff between risk and benefit is less clear with less precision, so that the values, age, and health of individual patients will likely lead to *varying* choices [4].

## Definition and Prognostication

In determining the appropriateness of critical care interventions, the clinician must assess

- (a) The overall quality of evidence supporting management.
- (b) Patient and surrogate decision-maker preferences, the risk: benefit ratio of the intervention, and consequent costs.
- (c) The validity of comparison between the patient being managed and the group from which the evidence base was derived.

The following questions delineate the DBI population and assist clinicians in determining the validity of comparison between the proposed population and the available data.

### What is the Definition of DBI?

The term DBI has previously been applied to patients who have (1)

- (a) Penetrating and/or blunt trauma to the brain or devastating stroke.
- (b) Been evaluated by neurosurgery and/or neurology.
- (c) Injuries deemed to be non-survivable and not amenable to neurosurgical intervention.
- (d) Ongoing resuscitation requirements by critical care services.

The panel opted to simplify the definition of DBI to include patients where there is an immediate threat to life from neurological cause upon presentation to hospital. Such simplification avoids exhaustive lists and

nomenclatural permutations and emphasizes the importance of clinical mortality risk assessment.

#### Recommendations

- We recommend defining DBI as
- Neurological injury where there is an immediate threat to life from a neurologic cause
- Severe neurological insult where early limitation of therapy (defined as treatment of disease, is being considered in favor of an emphasis on *care*, e.g., the provision of comfort measures)

(*strong recommendation/ expert opinion*).

#### How Accurate is Prognostication in DBI?

Scoring systems commonly used for patients suffering DBI summate physiological status and response to injury, often based on a single observation, usually around the time of presentation and diagnosis. Their prognostic utility is founded upon probabilistic models based on observations and population outcomes. Notably, there has been evolution of knowledge, therapy and technologies since the inception of these scoring systems, while the rate of mortality from ischemic stroke, subarachnoid hemorrhage, intracerebral hemorrhage, and brain injury [5–12] have all subsequently declined.

While these scoring systems have proven useful for gauging the immediate impact of disease and resultant life expectancy in cohorts of patients, when applied to the *individual* patient, they all share caveats of imprecision that limit their use and accuracy in both prognostication and clinical decision making. Kotwica et al. described a group of 111 patients with a Glasgow coma scale (GCS) of 3 on admission after brain trauma and showed that four went onto make satisfactory recoveries [5]. Although the majority died, it would be difficult to justify ceasing therapy on all patients with GCS 3 on admission, knowing that 3.6 % might have an acceptable outcome. While the Intracerebral Hemorrhage Scale score [13] demonstrated 100 % mortality at the upper extreme, the confidence may have been affected by a propensity for withdrawal of therapy [14], and larger studies ( $n = 3,255$ ) in populations with less tendency to withdraw demonstrate a reduction in predictive accuracy [15].

The Fisher scale is a radiologic assessment of blood volume calibrated to prediction of cerebral vasospasm [16], as distinct from clinical outcome, and recent trials have emphasized the importance of that distinction [17].

The World Federation of Neurological Surgeons (WFNS) scale combines GCS with lateralizing signs, and while there is a trended association with poor outcome [18], there remain conflicting reports of prognostic accuracy and limited ability to determine outcome between adjacent grades [19–21].

Similarly, the Hunt and Hess scale demonstrates limited ability to accurately predict outcome with an interobserver variability of only 0.42—which would likely preclude its acceptance and use were it to be introduced anew today [22]. Investigation of accuracy revealed that “many poor-grade patients achieved good recoveries and, therefore, that current admission grading scales are not accurate enough to be the sole basis for treatment decisions” [22].

It is also noteworthy that later assessments repeated on the day of operation proved of more prognostic value than the initial values on hospitalization [23].

A common principle in scientific observation allows that a lack of accuracy in observation may be compensated for by repetition of assessment in order to decrease error margins. In other words, predictive modeling allows that the accuracy of any model increases with the number of observations, and consequently adding more observations over time will increase confidence in the predicted result [24].

#### Recommendations

- We recommend determining prognosis from repeated examinations over time to establish greater confidence and accuracy (*strong recommendation, moderate quality of evidence*).
- We recommend applying these guidelines in the early stages of DBI treatment in order to maintain physiologic stability, even when early limitation of aggressive care is being considered. Such early implementation prevents unwarranted deterioration and allows sufficient opportunity for prognostic evaluation, care planning, and consideration of organ donation (*strong recommendation, moderate quality of evidence*).

#### What is the Impact of Early Prognostication (Before 72 h)?

The question of how much time is required for valid prognostication is important but not easily answered. It could be argued that the answer depends on both magnitude and direction of pathophysiological change. Nonetheless, an interval of 72 h is frequently used to determine both the initial effect of an injury and the subsequent trajectory of response [25–33].

Withdrawal of therapy contributes to variability in outcome and occurs in up to 76 % of patients dying from ICH [34]. Physician bias can significantly affect communication of prognosis [35] and may also induce inattention to the maintenance of physiological stability, fulfilling the prophecy of poor outcome [36]. Where death is more certain, premature decision making may compromise the opportunity for organ donation. In a population of patients with non-survivable gunshot wounds to the head, the only

discernible difference between organ donors and non-donors was early termination of life-sustaining treatment in the emergency department [37].

#### Recommendation

- We recommend using a 72-h observation period to determine clinical response and delaying decisions regarding withdrawal of life-sustaining treatment in the interim (*strong recommendation, moderate quality of evidence*).

### What Factors Identify Patients at High Risk for Death Due to Brain Injury?

Prognosticators vary depending on the specific etiology of DBI. In traumatic brain injury (TBI), pupillary changes, extremes of age, low Glasgow Coma Score (GCS), high Injury Severity Score (ISS), need for intubation, hypoxia, hypotension, coagulopathy, transfusion, and spine injury have all been associated with hospital mortality [5, 36, 38–42]. Composite scores have good but not absolute accuracy in forecasting outcome [5, 43–46]. Concurrent anticoagulation increases risk of death [47]. Gunshot wounds have higher initial mortality, but similar outcomes to blunt injury subsequently [48]. These are probabilistic relationships, with few absolute certainties. In subarachnoid hemorrhage (SAH), age, neurologic function, and the distribution of bleeding predict hospital mortality to some degree, but with limited certainty [41, 49, 50]. In ischemic and hemorrhagic stroke, mortality is associated predominantly with high NIHSS score, advanced age, low and worsening GCS, diabetes, and hematoma volume [51–55]. Fever, leukocytosis, and renal function are also modifiers of outcome [56].

Given the wide range of known prognosticators, the panel felt that individualized assessment of mortality risk is a crucial part of care of the DBI patient.

#### Recommendation

- We recommend that clinicians consider all known prognostic variables in determining risk of death and that prognostication be based on individualized assessment of risk factors rather than on clinical scoring systems (*strong recommendation, moderate quality of evidence*).

### Psychosocial Management

Care of the DBI patient should extend beyond the individual to his/her family, unless the patient previously expressed otherwise. Clinicians should also preserve a high degree of respect for cultural and religious beliefs in caring for DBI patients.

Most literature on the care of families of the critically ill focuses on the general ICU population, as opposed to on DBI patients in particular. Research specific to neuroscience patients concentrates on needs identification and is usually qualitative, which restricts generalizability across care settings. Very few studies investigate the impact of specific interventions on psychosocial functioning. These factors limit the specificity of recommendations that can be made regarding the psychosocial care of DBI patients and their families. Although most studies examining psychosocial care are low quality, the panel determined that strong recommendations were warranted owing to the very low risks involved in psychosocial care interventions, as well as the patient preferences expressed in the existing literature.

### What are the Needs of Family Members of Patients with DBI?

Despite the lack of DBI specific research, families of neuroscience patients in general consistently state similar needs: consistent, honest, understandable information [35, 57–66] emotional support from health-care professionals including reassurance that the patient is receiving the best possible care [58, 59, 62–67], and physical presence at the bedside and involvement in care [57, 60, 68].

There may be limited congruence between the needs identified by family members as important and the needs identified by clinicians as important, highlighting need for clinical education [64, 65].

#### Recommendation

- We recommend that clinicians anticipate family needs for information, allow proximity to the patient, provide emotional support, and assess for unmet additional needs specific to the individual(s) (*strong recommendation, low quality of evidence*).

### How Can Clinicians Effectively Meet the Needs of Family Members of Patients with DBI?

Inadequate communication by clinicians is consistently reported in critical care [69–72]. Families have cited communication barriers such as insufficient contact with physicians [69, 71] and inadequate provision of information [70, 72]. Associated stress may contribute to limited information retention and comprehension [73–75]. Care-giver discomfort with communication and emotional needs may also limit the frequency and quality of family interactions [73, 76].

Prognostic uncertainty is frequently encountered in the care of patients with DBI [58, 59, 61, 68, 70]. Interestingly,

disclosure of uncertainty by the health-care team may strengthen the family–clinician relationship [73]. Families value relief of uncertainty, even if the outcome is negative [61].

Improving communication with consistent and honest information [35, 57, 59, 61] provided in a caring, supportive manner is viewed positively by families [58, 59, 61, 70], as is physician availability and frequency of communication [59, 61]. Families value nurses' explanations of the patient's status [71], clarification of information from other providers [77], and coordinated, consistent, and compassionate delivery of information by the team [67, 77]. A structured program using a family support specialist has been shown to improve communication and the family experience [78]. Several studies identified the value of a designated individual who can provide medical information and support when the physician is unavailable [61, 71, 78].

Because family members value proximity to the patient and opportunity for involvement in care, these activities should be promoted [57, 59, 60, 66–68, 77, 79]. This extends to being informed of changes in patient condition [62–64, 66, 67].

#### Recommendations

- We recommend early, frequent, and consistent multidisciplinary communication regarding patient condition (*strong recommendation, low quality of evidence*).
- We recommend that clinicians provide clear information regarding condition and prognosis and include a discussion of prognostic uncertainty if appropriate (*strong recommendation, low quality of evidence*).
- Consider using a family support specialist to improve ongoing education and support (*weak recommendation, low quality of evidence*).
- Encourage proximity and involvement in care when desired by the family (*strong recommendation, low quality of evidence*).

#### How Do Surrogate Decision Makers of Patients with DBI Make Decisions About Treatment, and How Best Can We Assist Them?

Patient surrogates make up to sixty high-level decisions (medical, financial, personal, legal, and ethical) within a month of DBI; nearly a third of these are within the first 24–48 h [80]. Emotional shock, lack of information, prognostic uncertainty, and family reactions all impact upon decision-making processes [61, 71, 73, 80]. This may result in an “overload” of responsibilities. Surrogates may use internal (faith, intuition, perceived trajectory of recovery or decline) and external resources

(prior patient conversations, patient's culture and religious beliefs, physician prognostication) to aid their decision-making [71, 77] and may involve family members or religious support [71, 77]. The ICU nurse can also support and clarify physician-imparted information [67, 71, 77].

Identification of a legal healthcare proxy and their preferred decision-making style (shared, informed, paternalistic) are important initial steps in supporting decision-making. The paternalistic approach occurs when the medical team decides for the patient what care will be given. Informed decision making involves discussions between the proxy and the medical team with final responsibility resting with the proxy. Shared decision-making balances both medical caregiver and surrogate opinions to direct care. A positive relationship between surrogates and clinicians improves trust and decision-making [61]. Reviewing the content of advanced directives or personal conversations is necessary and helpful [71, 77].

Several factors improve how surrogates perceive the quality of end of life in the ICU. Again, the literature emphasizes the benefit of timely, clear, and compassionate communication and decision making focused on patients' preferences, goals, and values. Also important are maintaining comfort, dignity, and personhood, as well family care with open access and proximity to the patient. Interdisciplinary support (pastoral care and social service) and bereavement care can also be of use [58, 71, 77]. Presentation of options for where death will occur is also important. Whether the preferred locale of death is the hospital, hospice, or home, the logistics of how each would occur require discussion to determine the optimal plan [61].

#### Recommendations

- We recommend early identification of the healthcare proxy and their preferred decision-making approach (*strong recommendation, low quality of evidence*).
- We recommend prioritization of information sharing with the healthcare proxy, as well as staggering information delivery when possible to minimize cognitive and emotional overload (*strong recommendation, low quality of evidence*).
- We recommend focusing clinical decision-making on the patient's preferences, goals, and values (*strong recommendation, low quality of evidence*).
- We recommend assuring proxies that compassionate and quality care will continue regardless of withdrawal decisions (*strong recommendation, low quality of evidence*).
- We recommend early involvement of resources such as social services, religious leaders, and palliative care (*strong recommendation, low quality of evidence*).

## Ethics

Guidelines for the management of DBI patients would be incomplete without discussion of the ethical principles inherent in their care. However, clinical trials have yet to provide any good quality supporting evidence. Thus, the panel's informed perspective arises from the body of philosophical literature covering ethics in DBI, which is of variable quality and limited scope. Recommendations are provided with a strength and all are considered expert opinion.

At least two broad themes consistently arise in discussion of this topic. First, resuscitation must be initiated early enough to have any reasonable chance of creating benefit in terms of survival or preservation of organ viability. Second, the ethics of the management of DBI patients cannot be considered without recognizing the interface between care delivered and the likelihood of organ donation.

### Who Should be Resuscitated and Who Ought to Provide Consent?

Restoration of physiological homeostasis is central to TBI management [81]. Failure to resuscitate patients who have no known pre-existing objection to aggressive care (e.g., use of a do not attempt resuscitation [DNAR] order) may limit the opportunity for a degree of recovery or for successful organ donation. Exceptions to this may arise in resource-limited environments. If treatment is considered heroic and of such intensity that it limits resources for patients with greater chances of recovery, the obligation of aggressive early resuscitation may be relaxed, although principles of distributive justice in DBI are challenging because of the inherent inaccuracy of early prognostication [82].

#### Recommendation

- When resources allow, all DBI patients without a known pre-existing objection to treatment should be aggressively resuscitated for an initial period (see above) to maximize the likelihood of potential neurologic recovery or the opportunity for organ donation (*strong recommendation, expert opinion*).

Unidentified patients in extremis do present emergently and are assumed to provide consent for therapy based upon the "reasonable man standard," in that a reasonable person would likely request resuscitation in the situation. The poor prognosis of DBI may alter this presumption, but prognostication is only reliable after resuscitation, not before. There is also ample data to refute the certainty of poor outcome, even in DBI patients presenting with a GCS of 3 [83].

Assumed consent is required therefore to initiate resuscitation, and when appropriate might yield to surrogate

decision-making. Delays in care may increase the chance of a subsequent determination of medical futility. Conversely, surrogate requests for subsequent cessation of initiated resuscitation are substantiated legally and in practice [84, 85] and allow clinicians to discontinue treatment when not consistent with patient wishes (see Autonomy below) [86].

#### Recommendation

- The consent for initial resuscitation ought to be assumed unless there is a pre-existing known objection and should not be dependent on organ donor status (*strong recommendation, expert opinion*).

### How Should Organ Donor Status Affect the Care of the DBI Patient?

Debate exists on whether care teams ought to know the organ donor status of DBI patients during resuscitation. Knowledge of donor status may facilitate the tailoring of resuscitative efforts to patient wishes, e.g., preserving organ viability as a parallel goal. Alternatively, concern has arisen in the lay community that knowledge of donor status could alter care inappropriately, with the potential to diminish the resuscitative efforts provided [87].

#### Recommendation

- We recommend that notification of DBI patient donor status during the resuscitative period, if done, should not alter resuscitative efforts (*strong recommendation, expert opinion*).

### How Do Ethical Principles of Justice Apply in the Care of the DBI Patient?

Resuscitation of DBI patients can be extremely resource intensive. The potentially disproportionate use of resources for an individual patient with DBI might be mitigated by the successful return to an acceptable state of functioning for that individual, or barring that outcome, the successful transplantation of organs if the patient does not survive. Regardless of ultimate outcome, the use of these resources is justified even in situations in which the more likely outcome is death, rather than a return to function.

If organ donation is to be a secondary, but ethically viable and societally important outcome, it is imperative to guard against the corollary argument that those with viable organs ought to be resuscitated more aggressively than those without. Organs are not allocated on the basis of secondary value principles such as parenthood, occupation, or education; similarly, the resuscitation of the DBI patient

cannot hinge upon the likelihood of organ donation under current ethical standards.

#### Recommendation

- We recommend that the resuscitation of the DBI patient should not be dependent on the possibility of organ donation (*strong recommendation, expert opinion*).

Justice within health care involves equality as well as a moral obligation to adjudicate competing claims fairly, while maintaining an understanding of the scope of the competing claims [88]. There is no clear definition of futility in DBI nor is an acceptable definition likely to arise in the near future. Nonetheless, if care is truly futile, the impact on justice and resources must be appreciated. There is no moral obligation to resuscitate DBI patients when there is consensus on both futility of neurologic recovery and of organ donation.

#### Recommendation

- We recommend that if resuscitative efforts are futile and no option for organ donation exists, there is no prima facie obligation to continue to resuscitate the DBI patient (*strong recommendation, expert opinion*).

However, irrespective of determinations of futility or the possibility of organ donation, there is a moral obligation to prevent undue suffering [88]. Resuscitation can often complicate palliation; however, the relief of suffering must remain a primary principle of ethically delivered care. Palliative sedation has been employed in this manner at the end of life [89]. It deserves specific attention in the context of organ donation after cardiac death, with formal ethics consultation in developing a standardized policy. This safeguards against real or imagined drift toward euthanasia, overt, or otherwise [89].

#### Recommendations

- We recommend the use of appropriate analgesic and sedative medication in DBI patients to relieve undue suffering regardless of secondary circumstances, such as futility, organ donation, and need for prognostication (*strong recommendation, expert opinion*).
- We recommend that palliative sedation should not exclude the possibility of organ donation (*strong recommendation, expert opinion*).

#### How Should Issues of Autonomy be Addressed in DBI Patients?

DBI inhibits the expression of autonomy, which is a fundamental right in health care. Surrogate expressions of

autonomy, informed by pre-existing documentation (living wills, physicians orders for life-sustaining treatment (POLST) forms, durable powers of attorney for health care) or by legally authorized representatives exercising substituted judgment, are a crucial resource in providing ethical care to DBI patients without the ability to advocate on their own behalf.

#### Recommendation

- In the absence of evidence to the contrary, we recommend that DBI patients should be resuscitated in an attempt to respect autonomy (*strong recommendation, expert opinion*).

The patient with DBI may have wished to restrict resuscitation in a particular set of circumstances, but this is impossible to know a priori unless the information is present. If that desire for restriction becomes known, there is no moral obligation to continue with resuscitation, and there is an obligation to cease. Autonomy is usually patient-focused but does extend to clinicians; no one is obligated to provide care that they deem unethical [90]. The extent to which this provision applies to the DBI patient is questionable. If care is desired by a patient or a surrogate and is in conflict with the individual ethics of the clinician yet not generally prohibited ethically, the clinician in question must either render that care or identify an alternate who will do so [90].

#### Recommendation

- We recommend that clinicians respect legitimate directives to restrict resuscitative efforts in DBI patients (*strong recommendation, expert opinion*).

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